For Good Measure

HIV advocate Lepena Reid confronts weight gain.

November 2, 2020 By Alicia Green

Lepena Reid tested HIV positive in 1988, after spending the early ’80s caring for friends and others living with the virus and working with AIDS organizations.

“I didn’t start medications until about 15 years later,” says Reid, a 63-year-old advocate living near Tampa. “The reason was because many of the friends I saw were on [older drugs], and they were dying.”

Reid didn’t begin taking meds until 2002, when she ended up in the hospital with pneumonia. HIV aside, the worst health problem she’d experienced before that was an occasional cold. “I always ate healthy and exercised spiritually,” she explains. “I always had my belief in my faith. I just had that will to live.”

Reid’s HIV treatment has resulted in some physical changes—she has gained weight. By her count, she’s put on 20 pounds in the last two years.

In 2018, Reid and her doctor decided to switch her to a single-tablet regimen to reduce her pill burden. At one point, she had been taking three pills daily.

After the switch, Reid began to gain weight. She told her doctor and started doing research. She spoke with other people in the HIV community who shared their own experiences with weight gain.

She also learned that one component of the tablet—tenofovir alafenamide (TAF)—was associated with weight gain. In addition, the pill contains an integrase inhibitor, another possible culprit.

“I really eat healthy,” she explains. “I don’t drink alcohol, smoke or none of those things. My diet hadn’t changed, but my weight was increasing.”

Her new weight has made her feel uncomfortable and larger overall. “I’m very disappointed with my appearance right now,” she says. “When I look at myself and how my clothes fit on me, I don’t feel good about it.”

Nevertheless, Reid has kept up her wellness habits. She regularly eats vegetables, makes her own juices and walks twice a day. She doesn’t eat seafood but does sometimes enjoy chicken. Even so,

she still hasn’t lost any weight and considers her belly a problem area.

After observing no decrease in her weight, her specialist recently switched her HIV treatment to a different single-tablet regimen that does not include TAF but does contain an integrase inhibitor. Although she hasn’t shed any pounds yet, she is optimistic about the future. “I hope I can go back to my doctor soon, and they’ll do something else because these 20 pounds are just not comfortable for me,” Reid says.

What’s more, Reid is very worried about developing dementia, as she has a family history of the condition. She also knows HIV can affect brain function and lead to HIV-associated neurocognitive disorders.

Otherwise, Reid isn’t too concerned about her health.

Despite the ongoing COVID-19 crisis in the United States, Reid continues to facilitate support groups for women living with HIV, albeit via telephone. She also crafts red ribbon earrings—to raise awareness and support for HIV-positive people—as well as other jewelry as a member of Common Threads, a crafting collective of women living with HIV.

Reid plans to continue celebrating life—whether she’s spending time at the beach, crafting, skydiving, laughing or advocating for people living with HIV.

“I’m still alive,” Reid says. “If you’re alive, you have a possibility to do and create, and that’s what I want to continue to do as long as I live. I’m doing the best each and every day that I can for myself and my community.”

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